SCR

29

STATE OF ALASKA
1992 LEGISLATURE

BILL VERSION SCR 29
PUBLISH DATE 28-Jan-92

REQUEST:
Revision Date:
Title: Bone Marrow Donor Week
Sponsor: Cotten
Requestor: Senate HESS

Department Affec.ed DHSS
BRU:
Components:
COMPONENT SERIAL NO.

EXPENDITURES/REVENUES: (THOUSANDS OF DOLLARS)

OPERATING	FY 93	FY 94	FY 95	FY 96	FY 97	FY 98
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants, Claims						
Miscellaneous						
TOTAL OPERATING	0.00	0.00	0.00	0.00	0.00	0.00

CAPITAL						

REVENUE						

FUNDING: (THOUSANDS OF DOLLARS)

General Fund						
Federal Fund						
Other						
TOTAL	0.00	0.00	0.00	0.00	0.00	0.00

POSITIONS:

Full-Time	0	C	0	0	0	0
Part-Time	0	0	0	0	0	0
Temporary	0	0	0	0	0	0

ANALYSIS: (ATTACH A SEPARATE PAGE IF NECESSARY)

Prepared By: Melissa Fouse
Phone: 3818
Division: Senate HESS Committee
Date: 28-Jan-92

Approved by Commissioner: Senator Arliss Sturgulewski
Agency: Senate HESS Committee
Date: 32169

distribution: Leg. Fin., Legislative Sponsor, Requestor, OMB/DBR, Gov. Legis. Ofc., & impacted agencies

ALASKA STATE LEGISLATURE

☐ P.O. Box 770296
Eagle River, Alaska 99577
(907) 694-6683

☐ 3111 C Street, Suite 540
Anchorage, Alaska 99503
(907) 561-8459

☐ State Capitol
Juneau, Alaska 99801-1182
(907) 465-3711

SENATOR SAM COTTEN

TO: Senator Arliss Sturgulewski, Chair
SENATE H.E.S.S. Committee

FROM: Senator Sam Cotten

DATE: January 24, 1992

RE: SCR 29 Designating April 19 -25, 1992 as "Bone Marrow Donor Week"

As indicated by the title, this resolution would designate April 19 - 25 as "Bone Marrow Donor Week". I introduced SCR 29 in order to bring more attention to the efforts being made to promote involvement in the bone marrow donor program. Bone marrow transplants are used to successfully treat leukemia and other blood-related diseases. This particular week was selected at the request of the Blood Bank of Alaska to coincide with "National Organ Procurement Week".

Last year this committee passed a similar resolution. I am pleased to note that the Blood Bank of Alaska, the Eagle River Lions and Lionesses and numerous other groups were able to take advantage of the legislatively designated week and increased public awareness and involvement in the bone marrow donor program.

During Bone Marrow Donor Week in 1991 there were a number of events conducted throughout the state. One very successful activity was a type-testing drive right here in the capitol building which Rep. Betty Bruckman and her staff spearheaded.

Although the bone marrow donor program is an ongoing effort, designating one week in April will help increase the level of public awareness and facilitate promotional activities.

Eileen Albert

SCR 29 PACKET CONTENTS

1- SPONSOR STATEMENT

2- Article 4/25/92 Chugiak-Eagle River Star

3- Article 4/25/92 Chugiak-Eagle River Star

4- Letter of support for NBMDP, First Lady Barbara Bush

5- Article 10/8/90 Business Week

6- Blood Bank of Alaska Donor Information

7 National Bone Marrow Donor Program, General Information

BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE ALASKA 99508 (907) 563-3110

BLOOD BANK OF ALASKA IN CONJUNCTION WITH PUGET SOUND BLOOD CENTER UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

CONSENT TO JOIN A VOLUNTEER MARROW DONOR REGISTRY

Patrick G. Beatty, M.D., Associate Professor of Medicine
(206) 292-1897

Franc A. Fallico, M.D., Blood Bank of Alaska Medical Director
(907) 563-3110

INVESTIGATORS' STATEMENT

Purpose and Benefits

Leukemia and aplastic anemia are fatal diseases of the blood which can be treated with chemotherapy, immunotherapy, and/or irradiation. In some instances, bone marrow transplantation is the treatment of choice. Marrow transplantation permits the use of much greater doses of chemotherapy or irradiation in leukemic patients to destroy as many malignant cells as possible. Since these doses also destroy the patient's ability to make new cells, normal marrow must be provided from a healthy donor to rescue the patient. Most patients who might benefit from such treatment do not have a matched sibling available as a donor. We are recruiting a large number of volunteer unrelated bone marrow donors into a registry that would only be accessible to authorized personnel for matching potential donors with transplant candidates. There is no direct benefit to you as a result of joining the Bone Marrow Donor Registry.

Procedures

To be considered for the registry, a potential marrow donor must be between the ages of 21 and 55 and in good health. Entry in the registry does not commit a potential donor to donation. It only gives registry personnel permission to contact a potential donor for further discussion and additional blood tests if a closely matched patient is identified. Even at that time, the potential donor's name will not be released to the patient, the patient's family, or the patient's physician without the written permission of the donor. Although the potential donor has a legal right to withdraw at any point in the selection process, once the patient's pre-transplant chemotherapy and radiation treatments have been started, there exists a moral obligation to follow through with the marrow donation. The doses of drugs and irradiation are lethal to the patient without marrow rescue.

Volunteers for the bone marrow donor registry will be asked for their name, address, telephone number, birth date and, at their option, social security number (social security numbers will be used only for identification purposes). If blood has not already been drawn in the course of a routine blood donation, 4 teaspoons of blood will be drawn for tissue typing. Volunteers will be contacted approximately every two years to confirm continuing interest and update the address list. Registry data shall be kept locally. It is possible that a marrow donation may be shipped to recipients elsewhere in the United States.

Risks, Stress or Discomfort

At such time as you may be found to be a suitable match for a specific patient, the risks of the bone marrow aspiration procedure will be discussed in detail. In brief, these include the risks of general or local anesthesia and the anticipated pain, soreness and bruising from the needle punctures through the skin into the hip. The insertion of a needle to draw blood may cause temporary discomfort and a bruise may form at the site where the needle enters the vein. Details may be found in the accompanying information package. An additional consent form describing the aspiration procedure will be provided for signature at that time.

Other Information

There will be no costs to you for HLA typing or for entering your name in the marrow registry. Any expenses would be covered by the patient receiving the marrow. You are free to refuse to participate and to withdraw from the study at any time without penalty or loss of benefits to which you are otherwise entitled. Your identity will be kept confidential with only authorized local registry personnel having access to your identifying data. Your registry data will be maintained on file until you reach age 55.

INVESTIGATOR'S SIGNATURE ________________________________

DATE __________

SUBJECT'S STATEMENT

You may perform HLA typing on a research blood sample drawn from me. I agree to allow my name, HLA typing information, and results of any virology testing to be placed into a local registry at the Blood Bank of Alaska and also at Puget Sound Blood Center. I understand that my HLA type, but not my name, will also be entered into a national registry. I will not be charged for having my blood HLA typed or for having my HLA type entered into the registries. I may be contacted by the local registry personnel about further blood drawing and tissue typing if a patient who may benefit from my bone marrow is identified. This registry consent does not place me under any obligation to proceed with the donation process. I voluntarily consent to participate in this study. I acknowledge receipt of a signed copy of this consent form. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about subject's rights will be answered by a Blood Bank of Alaska representative.

SUBJECT'S SIGNATURE (For informational purposes only: keep this for your records.)

DATE __________

cc: Subject

Once people have donated, can they donate again?

Because the body replaces the donated bone marrow, it is medically possible to donate more than once. Although it is unlikely that someone would be called again, it's possible that a former marrow donor will later be found to match another patient. However, it is unlikely that we will ask a donor to give more than once to the same patient.

What are the risks for the donor?

It is possible to have a bad reaction to anesthesia, including sudden fall in blood pressure, abnormal heart beats and very rarely, death. However, to date, over 2000 bone marrow transplants have been performed is Seattle without a donor fatality. There have been rare instances of temporary complications such as fevers or greater than expected bleeding from aspiration sites.

INFORMATION ABOUT MARROW TRANSPLANTATION

Who needs bone marrow transplants?

Bone marrow transplants are used to treat patients with aplastic anemia (a disease in which the body stops producing blood cells) and some types of leukemia (a cancer of the blood). In both of these diseases, replacing the bone marrow with new, healthy marrow has markedly increased the chances of curing the patient's disease.

How is the patient prepared for the transplant?

For the patient, preparation begins well in advance of the transplant. The patient's diseased bone marrow is destroyed through the use of a combination of radiation and chemotherapy treatments.

At this point, there is no turning back for the patient. The marrow-destroying treatments are fatal in themselves, unless healthy marrow is immediately transplanted.

How do patients receive the marrow?

Patients receive the marrow much as if it were a blood transfusion. The marrow, a liquid resembling whole blood, is transfused intravenously into the patient's bloodstream. The transplanted marrow naturally grafts itself within the patient's bones, replacing the previously diseased marrow. During the transplant procedure the patient experiences virtually no pain.

What are the first signs that the transplant is a success?

Once the donated marrow enters the patient's bloodstream through transfusion, it takes about two weeks to see the first evidence of a graft, indicating that the new marrow has started to grow in the patient. A noticeable rise in the patient's white blood cell count is the first sign that the graft has occurred. The white blood cell count will continue to increase, and eventually there will be evidence of marrow production of platelets and red cells as well as white cells.

What complications does the patient experience?

In addition to side effects caused by chemotherapy and radiation treatments used to prepare the patient for transplant (nausea, vomiting, hair loss, diarrhea, and appetite suppression), there are several complications that may result from the transplant itself. These include rejection (no graft occurs); graft-versus-host disease (the new marrow tries to reject the patient's body and causes infection and inflammation); infection (the result of destroying the patient's entire immune system in preparation for transplantation); and relapse (the original disease reappears in the bone marrow).

Can such complications be treated successfully?

Most of these complications have been treated successfully. Response to treatment is directly related to the severity of the problem. In the most severe cases the patient's chances for survival are poor.

May the donor meet the patient who receives his or her bone marrow?

If both parties are agreeable, donors may meet their bone marrow recipient at such time after transplant that engraftment is ensured and there are no medical problems. However, donors are told about the recipient's condition at the time they agree to donate and may, with the patient's consent, continue to receive progress reports during the patient's hospital stay and beyond, if they wish.

BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE, ALASKA 99508
(907) 563-3110

BLOOD BANK OF ALASKA
AND
PUGET SOUND BLOOD CENTER BONE MARROW DONOR PROGRAM

Previously, patients in need of a bone marrow transplant could be helped only if there was a tissue-matched donor within the family. Now, those without a matched related donor can be treated for such diseases as leukemia and aplastic anemia by receiving bone marrow from a healthy, unrelated donor.

However, in order to locate suitable unrelated donors for patients who need marrow transplants, there must be a pool of HLA-typed volunteers (HLA stands for human leukocyte antigen). The decision to become one of these volunteers requires serious consideration. This information package is designed to provide you with answers to commonly-asked questions about the marrow donation process and the transplant procedure. We hope this information will enable you to make a knowledgeable decision about joining a volunteer bone marrow donor registry.

BONE MARROW DONOR INFORMATION

Who qualifies as a bone marrow donor?

Unrelated volunteer donors must be between 21 and 55 years of age and must pass a comprehensive physical exam. Furthermore, their HLA type (tissue type) must match that of a patient who needs a bone marrow transplant.

What is an HLA type and how is it used?

The HLA type classifies people according to marker antigens on the surface of their white blood cells. The marrow of the donor whose HLA type matches that of the patient is much more likely to "take" than one that does not match.

What are the odds that an unrelated donor's HLA type will match that of a potential transplant candidate?

The odds are between 1 in 10,000 and 1 in 100,000 that any two unrelated individuals will have matching HLA types. Thus, it is critical to maintain a donor file with as many members as possible to increase the chances of finding a matched donor for every patient.

How are donors located?

Although physicians prefer family members because they offer the greatest chance of a successful transplant, only about 40 percent of those who need a transplant have a compatible related donor. For the 60 percent who don't, we must recruit donors from the general population. Nationwide, a central registry of over 200,000 people has been started to meet the country's requirement for unrelated bone marrow donors. A worldwide goal of one million donors has been targeted.

What laboratory tests are used to match donor and patient?

Everyone who agrees to enter the registry has a blood sample drawn to determine a preliminary HLA type. Later on, if this preliminary typing indicates that a donor may match a transplant candidate, another blood sample will be drawn for additional testing to confirm a perfect match.

How do matched donors learn more about what's involved in donating bone marrow?

Once the laboratory tests have confirmed that the donor is matched with a patient, the volunteer must decide whether to make the commitment to donate. Arrangements will be made for him or her to meet with a Blood Bank of Alaska or Puget Sound Blood Center physician to discuss the donation process.

After discussing the donation procedure, the potential donor is asked if he or she will sign the hospital consent forms authorizing the donation of bone marrow. At this point, the individual makes the final decision about donating before the patient is started on pre-transplant conditioning therapy. This is the point of "no return." The severity of the treatment means that the patient will die without a bone marrow transplant. Two weeks before the scheduled transplant date, the patient begins chemotherapy and radiation treatments designed to kill the diseased marrow. These treatments also allow the donated marrow to implant in the patient's marrow cavities and grow.

Can a matched donor say no?

Deciding to participate in a bone marrow transplant is a serious matter for all concerned. There may be many reasons for a potential donor who is perfectly matched with a transplant candidate to say "no." These reasons include such considerations as poor health, time involved, or concern about the risks. Even for related-donor transplants, family members sometimes decide against giving their marrow. Furthermore, whether potential donors agree to participate or not, their identities remain confidential. Although the potential donor has a legal right to withdraw at any point in the selection process, once the patient's pre-transplant chemotherapy and radiation treatments have been started, there exists a moral obligation to follow through with the marrow donation. The doses of drugs and irradiation are lethal to the patient without the marrow rescue.

How is a donor's health evaluated?

Once consent for the marrow donation is given, donors undergo a complete physical examination by a physician who is knowledgeable about marrow donation but who is not employed by the Blood Center or by the Transplant Unit. The physician represents the donor and determines that the donor's health will permit a safe transplant for both donor and recipient.

Is the donor required to follow any special procedures before giving marrow?

There is no need to make any changes in diet, work, or social habits before the bone marrow donation, although we usually recommend that iron tablets be taken for a few weeks before donation to expedite replacing the blood present in the marrow. Iron tablets can cause stomach irritation which resolves if the medicine is stopped. Also, during the week before the procedure a donor should not take any unnecessary risks such as riding motorcycles, flying a small aircraft, etc. since his health is vital for the patient.

What's the first step in becoming a volunteer marrow donor?

The first step is to agree to participate in a marrow transplant registry by completing the Bone Marrow Donor Data form enclosed. When we receive your completed form, we will contact you to set up an appointment to come in to the Blood Bank of Alaska. Also, we will need to draw a blood sample for HLA typing.

If I register as a volunteer marrow donor, what are my chances of actually being used as a donor?

There are common and uncommon HLA types. If yours is a common type, the chances that you will match a transplant candidate are much greater than if your type is rare. It's possible that you will never be called. But if you are, you will always have the option of deciding not to donate.

If I'm found to be a matched donor and agree to proceed, who covers my expenses?

Expenses incurred for medical examinations and hospital stay are paid by the transplant patient's medical insurance. Travel expenses and other non-medical costs are also the patient's responsibility. Life and disability insurance policies covering the procedure are provided by the patient to the donor at no charge. The patient shall be responsible for any required followup care of the donor if complications occur. Compensation for loss of work is handled, if necessary, on a case-by-case basis with the donor's employer.

What's involved in removing the donor's marrow?

Bone marrow for transplantation is removed from the hip bones during an aspiration procedure. All donors receive some form of anesthesia--either a general anesthetic, which puts you to sleep during the procedure, or a spinal anesthesia to deaden feeling in the area of the body where the punctures are made in each hip. Twenty to thirty extractions of marrow are made through each of these punctures to draw the marrow out of the bones. Typically, the donation procedure lasts from 45 to 90 minutes.

Between 3 to 5 percent of the total bone marrow is removed, an amount not large enough to cause anemia. The donor will also usually receive a pint of their own blood taken and stored one to three weeks before the donor's marrow donation. Within several weeks, the marrow will be replaced by normal processes. Except for some soreness in the hips that may last for a few days, donors generally experience no other problems.

Where will the donation take place?

Because a highly trained physician specializing in marrow aspiration must perform the aspiration, donors from Alaska will be flown to Seattle, where the aspiration will take place. All costs associated with the travel and hospitalization of the donor will be covered by the patient's insurance.

When and for how long is the donor hospitalized?

Typically, the marrow donor enters the hospital the day of the donation. Because of the effects of the anesthesia, and because the donor's hips may be painful from the aspiration of marrow, donors usually remain in the hospital for one to two days.

After the donation, how long does it take to get back to normal?

The time required for a complete recovery varies but most donors resume their usual activities in a few days. Others may take up to a week but rarely longer.

BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE, ALASKA 99508
(907) 563-3110

BONE MARROW DONOR DATA FORM

PLEASE RETURN TO THE BLOOD BANK OF ALASKA, INC.

Date: ____________________

Please provide the following information as you wish it to appear in your Bone Marrow Donor Program permanent file. Notify the Blood Bank of Alaska, Inc. of any name, address, or telephone changes. [This information does not appear in the Bone Marrow National Registry. Only your HLA typing data and an identifying code will appear in the Registry.]

Name (print): ______________________________

Permanent Address: ______________________________

City: ____________________ State: ______ Zip: ____________

Social Security No.: ____________ Date of Birth: ____________

Home Phone: (____)____________ Work Phone: (____) ____________

Person(s) to contact if we cannot reach you at the above address or phone number(s). Please list as many names as possible.

Name: ____________________ Phone: (____)____________

Name: ____________________ Phone: (____)____________

Name: ____________________ Phone: (____)____________

Name: ____________________ Phone: (____)____________

Have you ever donated blood at the Blood Bank of Alaska? Yes ____ No ____

Approximate date of last donation ________/________.
Month Year

Optional Information: Certain HLA types are more common in various ethnic groups. Indicate which ethnic group you are a member of in order to assist in matching donors with patients.

1. ______ Caucasian
2. ______ Black
3. ______ Oriental
4. ______ Alaska Native
5. ______ Native American
6. ______ Hispanic
7. ______ Other
8. ______ Decline to Answer

B.B.A. USE ONLY:
Date and time HLA Specimen drawn: ______________________________

MEMBER OF AMERICAN ASSOCIATION OF BLOOD BANKS
MEMBER OF NATIONAL CLEARINGHOUSE PROGRAM

AIDS INFORMATION SHEET

WHAT IS AIDS? AIDS (Acquired Immune Deficiency Syndrome) is a condition in which the body's normal defense mechanisms against certain diseases or conditions are reduced. As a result, patients often develop unusual infections, such as Pneumocystic pneumonia or a rare form of skin cancer, Kaposi's Sarcoma.

WHO IS AT RISK? If you are an individual in any of the following categories, or if you are the sexual partner of an individual in any of the following catergories, you are at high risk of contracting the disease:

- Those who have one of its signs and symptoms such as: unexplained weight loss; night sweats; blue or purple spots typical of Kaposi's sarcoma on or under the skin, or spots or unusual blemishes in the mouth; fever over 99 degrees for more than 10 days; persistent cough and shortness of breath; swollen lymph nodes lasting more than one month; persistent diarrhea; or individuals who have had positive anti-HIV test results.
- Past or present abusers of intravenous drugs.
- Males who have had sex with another man, even one time since 1977.
- Persons born in or emigrating from countries where heterosexual activity is thought to play a major role in transmission of HIV-2 infection (e.g., sub-Saharan Africa, and islands located near these areas of Africa).
- Individuals with Hemophilia or related clotting disorders who have received clotting factor concentrates.
- Men and women who have engaged in sex for money or drugs since 1977, and persons who have been their heterosexual partners within 12 months.
- Persons who have had, or been treated for, syphilis or gonorrhea (Clap, the Drip, Strain, Louies, Bad Blood) during the preceding 12 months.
- Persons who have received a transfusion of whole blood or a blood component within the past 12 months.

The Blood Bank of Alaska is not a diagnostic service. There is an interval during early infection when the HIV antibody test may be negative although the infection may still be transmitted. If you are interested in your HIV antibody status, the Public Health Service located at 825 L Street provides testing and counseling for a nominal charge which may be waived if necessary. Call 343-4611 for additional information.

BONE MARROW DONOR HEALTH HISTORY

NAME: ____________________ DATE: ____________

SOC. SEC. No. ____________________ DATE OF BIRTH: ____________

1. Y( ) N( ) Are you between the ages of 21 and 55?
2. Y( ) N( ) Are you in good general health?
3. Y( ) N( ) Have you read and do you understand the "AIDS Information Sheet" and the "Bone Marrow Donor Information" handout?

NOTE: "YES" answers to the questions below do not automatically disqualify you. Please explain any "yes" answers in detail in the space provided below so your response can be properly evaluated.

4. Y( ) N( ) Have you ever been refused as a blood donor or had problems donating blood?
5. Y( ) N( ) Have you ever had cancer, diabetes, blood disease, or other chronic illnesses?
6. Y( ) N( ) Have you ever had chest pain, shortness of breath, heart attack, or other heart disease?
7. Y( ) N( ) Have you ever had hepatitis, yellow jaundice, liver disease, or a positive test for hepatitis?
8. Y( ) N( ) Have you ever had a positive test for AIDS antibodies? Have you ever been exposed to anyone with AIDS or with a positive test for AIDS antibodies? (Please refer to the AIDS Information Sheet.)
9. Y( ) N( ) Have you received any blood transfusions or tattoos during the past 12 months?
10. Y( ) N( ) Have you ever had malaria, or taken preventative medicine for malaria?
11. Y( ) N( ) In the past month have you taken any prescription drugs? (list below)
12. Y( ) N( ) Have you ever taken pituitary growth hormone or the medications Accutane or Tegison?
13. Y( ) N( ) Have you ever taken drugs by needle not prescribed by a physician, or have you ever had sex with someone who has?
14. Y( ) N( ) Have you taken clotting factor concentrates for a bleeding disorder such as hemophilia, or have you had sex with someone who has?
15. Y( ) N( ) Have you had, or been treated for, syphilis or gonorrhea in the past 12 months?
16. Y( ) N( ) Have you taken money or drugs in exhange for sex any time since 1977?
17. Y( ) N( ) Have you given money or drugs to someone to have sex with you at any time in the past 12 months?
18. Y( ) N( ) MALES: Have you had sex with another man since 1977 (even one time)?
    Y( ) N( ) FEMALES: Have you had sex with a man who has had sex with another man (even one time) since 1977?
19. Y( ) N( ) Were you born in or have you moved to the U.S. from Sub-Saharan Africa or the islands close to that part of Africa, or have you had sex with someone who has?

EXPLANATION(S) TO "YES" ANSWERS (except No. 1,2,&3): ____________________

____

SIGNATURE ____________________ FULL NAME ____________________

(please print)

BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE, ALASKA 99508 (907) 563-3110

CONSENT TO JOIN A VOLUNTEER MARROW DONOR REGISTRY

SUBJECT'S STATEMENT

You may perform HLA typing on a research blood sample drawn from me. I agree to allow my name, HLA typing information, and results of any virology testing to be placed into a local registry at the Blood Bank of Alaska and also at Puget Sound Blood Center. I understand that my HLA type, but not my name, will also be entered into a national registry. I will not be charged for having my blood HLA typed or for having my HLA type entered into the registries. I may be contacted by the local registry personnel about further blood drawing and tissue typing if a patient who may benefit from my bone marrow is identified. This registry consent does not place me under any obligation to proceed with the donation process. I voluntarily consent to participate in this study. I acknowledge receipt of a signed copy of this consent form. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about subject's rights will be answered by a Blood Bank of Alaska representative.

SUBJECT'S SIGNATURE:____

DATE:_________________________

cc: Subject

9/17/90

TEN COMMON QUESTIONS ABOUT THE NATIONAL MARROW DONOR PROGRAM

1. What is the National Marrow Donor Program (NMDP)?

The National Marrow Donor Program (NMDP) is a network of Transplant Centers (who care for patients), Donor Centers (who guard our volunteer donors' safety and confidentiality), Collection Centers (medical centers which meet our standards for marrow collection) and Recruitment Groups (which assist the NMDP in recruiting new volunteers for the national registry; many NMDP Donor Centers also are aggressive recruitment arms of the NMDP).

The NMDP Coordinating Center is located in St. Paul, MN and the computerized Registry is at the University of Minnesota. The Registry is the most sophisticated biometric program ever run by the U of M and is one of the most sophisticated in the world. NMDP has a contractual relationship with the federal government, through the National Heart, Lung, and Blood Institute, to run a national registry.

NMDP has only been in existence since 1987 and has experienced rapid growth, especially in the last six months. This has been made possible because of the generosity of hundreds of thousands of Americans, willing to be the stranger who offers the living gift of life. NMDP now is facilitating about 25 transplants a month. Admiral Zumwalt, NMDP Chairman of the Board has stated that the goal is 25 transplants a day.

We are also a research organization, studying the efficacy of marrow transplants and related treatments. NMDP has created a "bank" of cell line samples which has the potential for offering exciting insights into blood diseases and genetic disorders.

NMDP is funded, in part, by Congress through the National Heart, Lung and Blood Institute (part of the National Institutes of Health). The NMDP also solicits charitable contributions for assistance in typing volunteers and other recruitment efforts.

2. How many donors are on the Registry?

By the middle of September, 1990, over 200,000 people have volunteered and are included in the Registry. That number is doubled when you include volunteer donors from other countries, and it is expected to continue to grow nationally and internationally.

Volunteering to be a donor is not appropriate for everyone because of the commitment of time (about 40 hours in all, including counseling sessions, a complete physical and the approximately 24 hour hospital stay) and the need to use anesthesia when aspirating the marrow from the back of the pelvic bone. The discomfort felt after the donation has not been a major issue with donors (for a few days, there's a soreness described as similar to the feeling after falling on ice, on your derriere). However, because of the anesthesia factor, NMDP insists that all of its volunteer donors are between 18 and 55 and in excellent health. Many of NMDP's volunteer donors have become strong advocates for the Program.

Marrow completely regenerates itself in about 15-30 days. That's why this gift of a stranger is called the "living gift of life."

2A. How many donors do you need to match all the patients who request a marrow transplant?

We don't know. Yet.

Depending on how common a patient's Human Leukocyte Antigens (HLA) are, the chances of finding a match may range from one in 100 to one in a million. The odds of finding a match are better within a patient's own racial group.

NMDP set a preliminary goal of 100,000 donors for the United States and met that goal ahead of schedule. It became clear as we moved toward that goal that we would need more donors to match certain types of patients, especially those from American minority populations. It also has become clear that unrelated marrow transplants are a global hope. Because of computer technology, it is possible to have a worldwide registry of volunteers. Marrow can -- and has been -- exchanged between countries. NMDP has a goal of one million volunteer donors <u>worldwide</u>; 250,000 volunteers is NMDP's new U.S. goal. The U.S. goal includes expanding the ethnic diversity of this nation's registry to reflect the diversity of the country's population. Because of the efforts of people all around the world, NMDP believes that its goal can be reached by 1995.

While NMDP's goal continues to be to find a "miracle match" for everyone who needs a marrow transplant, medical science may prove this to be impossible. Even with a large pool of potential donors, patients who have a rare or unique "HLA typing" may never find a match, no matter how large the pool of volunteer donors.

3. How many transplants have been done?

By the end of July, 1990, NMDP will have facilitated over 400 transplants, half of them for people under the age of 25. Of the patients receiving transplants, 77% had some type of leukemia. Other transplant patients have had Myelodysplasia, Hodgkin's lymphoma, Non-Hodgkin's Lymphoma, Severe Aplastic Anemia (6.8%), Fanconi's Anemia, Osteopetrosis, Severe Combined Immunologic Deficiency, or other malignancies or non-malignant diseases.

Marrow transplants are being considered for patients with other types of cancer and other blood diseases. For example, research is being conducted to determine the efficacy of using marrow transplants to treat patients with Sickle Cell Anemia, AIDS and other genetic blood disorders. It is too early to speculate about the potential success or failure of these research efforts. NMDP officials continue to monitor these medical developments.

4. What's the Success Rate?

The standard answer is not a concise one. Early data indicate that the success rate is between 30 and 80 percent, depending on the disease of the patient being treated, stage of disease and age and condition of the patient.

Initially, many patients who chose transplantation made that choice after all other options had been exhausted. This resulted in less than physically ideal circumstances for the patient, who may have been weakened by many rounds of chemotherapy or the disease itself.

The rigorous pre-transplant conditioning can be fatal, as marrow transplantation has become a more common treatment, patients are being referred for transplant earlier. In general, early referral and a "quick match" assures a better outcome for the patient. Although the data is preliminary, it appears that unrelated donor transplants may have the same success rate as sibling transplants. With related donors, the chance of success can be as high as 90%, depending on the patient's disease and stage of disease at the time of transplant.

If the patient is alive and well three to five years after transplant, the probability of disease coming back is remote. There are patients currently alive and well nineteen years post transplant. Among patients receiving unrelated donor transplants, the longest living survivor is over seven years post transplant. NMDP's first transplant was done on December 15, 1987. It will be at least two to three years before NMDP can offer definitive numbers regarding success rate.

5. Does everyone who needs a transplant receive one and how much does it cost?

No, many patients are not referred for transplant, currently cannot find a matched donor or are too ill to undergo a transplant once a match is found. Other patients are not insured or underinsured and cannot afford or choose not to undertake the expensive and exhaustive process. Currently, NMDP is finding matches which result in transplant for 20% of the patients who search the NMDP Registry.

The average cost is approximately $150,000. From initial studies, marrow transplantation is more cost efficient than maintenance or "palliative" procedures which must be undertaken numerous times. Also a marrow transplant can cure if successful. For a leukemia patient or an aplastic anemia patient, other treatment usually only temporarily treats the symptoms of the disease.

Increasingly, health insurers are providing coverage/benefits for the cost of unrelated transplants as their experts review data on the successes achieved from this treatment. There is continuing concern over the hesitation by some payers to cover the donor search process and by some state governments to cover transplantation of any kind for medical assistance recipients.

Most of the cost of a transplant is the extended stay in isolation until it is determined there is sustained engraftment of the new marrow. About 10% of the overall expense is the cost of actually searching for an unrelated donor. The search includes extended tissue typing (HLA typing)/cultures/donor counseling and a thorough physical exam, marrow collection and transport. NMDP continues to work with health care insurers to educate them about the procedure and why this portion of the cost should also be paid by the company.

6. Does NMDP encourage the efforts by individual families to increase the size of the registry?

With the help of Congress, the NMDP was established. The Program is hailed as a model for transplantation coordination and has progressed rapidly, exceeding all of our preliminary goals and expectations. Because of this success, many American families who held no hope for a loved one have now placed their hope in finding a match for the special person in need.

To build a satisfactory donor pool, NMDP is in need of three basic elements;

A. More Americans willing to offer the "living gift of life" by volunteering to become a part of our Program. Currently, there is an especially critical need for minorities to volunteer.

B. The funds (private and/or public) to pay for the typing test. It costs approximately $65-$75 to do partial typing of new recruits. Of all the challenges confronting NMDP, HLA test funding has been the toughest to surmount.

C. Time to allow other countries to establish their own registries. This worldwide effort offers the best hope for patients seeking a matched donor. NMDP is vigorously encouraging development of registries in other countries.

While NMDP continues to seek private source funding to cover the significant HLA typing costs and to expand the registry internationally to allow for more diversity of the donor pool, the organization is also sensitive to the urgency felt by patients waiting today. Many families have launched local recruitment efforts when a matched donor was not immediately available through the registry.

NMDP encourages families to contact the NMDP Coordinating Center where staff members are available to advise families about where to call for help and how best to proceed. NMDP officials also maintain a strong sense of concern for both patient and donor. This concern is integrated in the counsel given to families.

Because of the efforts of some families for their own loved one, the registry's volunteer pool continues to grow and other lives continue to be saved. This wonderful registry would not be possible if not for many "determined moms and dads."

Volunteers recruited in patient-specific drives sign consent forms which make them available to any patient searching for a matched donor.

7. How are searches done with other countries?

International developments are one of the most exciting efforts underway at NMDP. Currently, The Netherlands is, and Israel will soon be, a part of NMDP's computer registry. Searches are "traded" (usually by facsimile) with the United Kingdom, Canada and France. NMDP anticipates that other European countries will become affiliated with the U.S. registry within the next six months. Japan and the Soviet Union are also considering creating a registry, and informal requests have come from many other nations offering opportunities for communications across political boundaries.

8. How long have you been doing searches?

Since September, 1987. The first transplant was done in December, 1987. The 100th transplant was done in February, 1989; the 200th in October, 1989; the 300th in March, 1990.

9. Why are you targeting minority communities for donor recruitment?

In the same way that you inherit your skin color or your hair color, you inherit your tissue type. This tissue typing must match between patient and donor to allow the best chance of success of the transplant.

For this reason, patients go first to their relatives when they are seeking a matched donor. About 25 percent of patients needing a transplant find a sibling match, the rest must turn their hope to NMDP.

Currently, 92 percent of the NMDP volunteer donors are Caucasian. It is of critical importance that NMDP reach members of minority communities and stress the urgent need for volunteer donors so the same hope can be offered to all Americans in need.

10. How do I become a donor?

The NMDP has set up a network of NMDP donor centers (local blood bank organizations). Coordinators at these centers counsel potential donors and work with NMDP when someone is identified as a potential match. Only the donor center knows the name of a donor, assuring protection and anonymity of the donor. However, these donor centers are facing challenges and limitations of time, space and funding for typing. NMDP continues to assist these centers in overcoming these limitations.

Those who are interested in volunteering may contact their local donor center or call NMDP. In many communities, local drives are held, spearheaded by an individual family or one of NMDP's grassroots groups such as Heart of America, NMDP's Donor Center Without Walls. Always, there is concern about raising the funds to pay for the HLA typing of those generous enough to volunteer as donors. Personal and corporate contributions and some funding from blood centers have been used in these efforts.

If a newspaper, television or radio station chooses too inform their audience about where to call for more information, **NMDP's public toll-free number is 1-800/654-1247** For business-related calls to the NMDP, please call 800/526-7809.

THE WHITE HOUSE

Dear Friends,

It is a pleasure to send this message of gratitude and encouragement to all those who are responding to the need for more volunteer bone marrow donors throughout our country.

Today, because of the generous spirit of hundreds of thousands of Americans, many patients with fatal blood diseases have received the chance of a lifetime. This spirit has now traveled to many other countries as well, thus providing a larger pool of volunteer donors and a sense that this world is a little bit better because strangers are giving the living gift of marrow. But so many more people are still on waiting lists, hoping and praying that someone will donate marrow that matches their own. The National Marrow Donor Program is making it possible to build this worldwide network of hope and help.

I salute everyone who is participating in donor recruitment efforts. May your commitment bring each of you a sense of satisfaction that you are part of a global lifesaving effort.

Warmly,

Barbara Bush

Volume XXI, Number 17 April 25, 1991

Community joins in donor search

The community turned out Monday night in great numbers to aid leukemia victim Eileen Albert — so much so that emergency purchases of more salad fixings cleared out produce counters at both Eagle River supermarkets.

"One woman said it reminded her of the way Eagle River used to do things. That really made my heart glow," Joe Kapella, one of the organizers, said of the widespread community support. Kapella, who often can be found twisting arms and selling tickets for local causes, said the spaghetti feed raised about $8,000.

A total of 1273 dinners were served during the 4-10 p.m. event, Kapella said. Lines extended through the North Slope Restaurant and on the sidewalk outside. At times there was a wait of up to 35 minutes. "They all waited patiently," he observed.

Also pleasing to sponsors was the large number of volunteers. "There were so many who wanted to help, that we actually had to turn some of them away," Kapeila said. "People just wanted to help. One lady stopped in and dropped off a hundred-dollar bill."

Douglas "Satchmo" Everton was one volunteer who was especially appreciated, Kapella said. An entertainer at The Fly By Night club in Spenard, Everton learned of the benefit when he stopped in for a hamburger Sunday evening. He came back on Monday with his guitar and made the wait pleasant for those standing in line.

People waited patiently for spaghetti dinners Monday night in a drive to benefit Fire Lake schoool nurse Eileen Albert's search for a bone marrow match. The community has rallied with blood samples for entry into a national registry, and with contributions to help offset costs of tests and marrow search. STAR PHOTO BY DEBBIE BRISCOE

Chugiak - Eagle River residents have rallied to aid Albert, school nurse at Fire Lake Elementary. She has leukemia and is searching for a bone marrow donor. If a match can be found from blood samples, a transplant is her only chance for survival.

Albert's plight has caught the attention of the community. Hundreds of people have given blood samples which are tested and entered into a national registry. A sampling center has been set up at the local office of the American Cancer Society in the Valley River Center building which houses the library. It is staffed by volunteers who take and record samples to be sent Outside for testing.

The testing program is being conducted by the Blood Bank especially appreciated," [illegible] said. An entertainer at The Fly By Night club in Spenard, Everton learned of the benefit when he stopped in for a hamburger Sunday evening. He came back on Monday with his guitar and made the wait pleasant for those standing in line.

[illegible]

and is searching for a bone marrow donor. If a match can be found from blood samples, a transplant is her only chance for survival.

Albert's plight has caught the attention of the community. Hundreds of people have given

the American Cancer Society in the Valley River Center building which houses the library. It is staffed by volunteers who take and record samples to be sent Outside for testing.

The testing program is being conducted by the Blood Bank

school budget advisory commission advice to trim $2 million — a position which was backed by mayor Tom Fink who threatened to veto that much.

Assemblyman Craig Campbell, who last year had been active in reducing the amount asked by the former superintendent, moved for adoption of the 1991-92 budget.

"We shouldn't subvert the board," Campbell said. He said the board had set its priorities and that all of the increase is going into the classrooms.

While there has been efforts among his constituents to reduce

Transplant gives new lease on life

By DEBBIE BRISCOE
Of the Star Staff

When Eileen Albert, a local nurse in need of a bone marrow transplant, needed help, the community responded. As of last week, almost 400 residents have given blood to see if their marrow is compatable with Albert's. Benefits and fund-raisers have become common place.

Stacey Grohol, a woman who fought luekemia and won, is thrilled with the community's outpouring of generosity.

Even though it's possible a match will not be found for Albert, it is possible a match will be made for another cancer patient in need of a transplant. All blood samples are listed with a national registry.

"It's a chance to save somebody's life. You're giving of yourself to save someone's life and if I could do it, I'd do it in a minute," Grohol said.

"You find a lot of people reach out to you when in need. Especially up here in Alaska," she said. "Alaskans seem to feel like when one of their own is in need, they need to take care of them. There's a kinship. I see that happening with Eileen."

Grohol had a lot of community support as well when she was first diagnosed with cancer, including the Eagle River Lions club, one of the organizations helping Albert. Articles were written about her and the things people were doing for her but she never kept a scrapbook.

"At the time, I didn't want to remember it. As far as I was concerned it wasn't something that was going to be a cherished memory," the 33-year-old said. "But now I look back on it and it was something I had to go through to go on living. So in that respect it's a good memory."

Grohol was diagnosed with chronic mylocetic leukemia in September, 1985, when she was just 28 years old. She and her husband, John, had just recently had a baby. Cancer was the last

(Continued on Back Page)

Stacey Grohol is able to share growing up with her son, John Christopher, because she received a bone marrow transplant which stalled leukemia's threat to her life. STAR PHOTO BY DEBBIE BRISCOE

R.D. Cheeley highway shoot

Raymond D. "R.D." Cheely, 19, Chugiak, was found guilty of second degree murder Saturday in connection with the Oct. 19 shooting death of Jeffery Cain, 20. Cain, an Eagle River resident, was the passenger in a sports car traveling southbound on Glenn Highway. At the same time, Cheely was driving an AMC Eagle which belonged to Douglas Gustafson, 18.

Prosecutors blamed Cheely for goading Gustafson into shooting at the sports car as it turned off the highway onto the Muldoon Road exit, and maneuvering into position so he could get a better shot. Gustafson, convicted of second degree murder Mar. 12, had been charged with firing the fatal shot from an assault rifle. The bullet went through the sports car's tinted back window, striking Cain in the head and killing him instantly.

Prosecutors said Gustafson and Cheely had purchased the weapon and earlier in the day

Brother provides marrow match

(Continued from Page 1)

thing the new mother expected to have to deal with.

"My son was five months old at the time. I thought I was just fatiqued," she said. Grohol went to the doctor for a kidney infection and the doctors found she had a high white blood cell count. Six months later she had a bone marrow transplant.

"Michael, my oldest brother, was the donor. They tested all my brothers and sister and both my parents. Everyone wanted to be the one who matched and Michael was a perfect match." she said.

She had to leave her baby, John Christopher, with her husband and his parents while she was in Seattle. She also made out a will to arrange for her infant's care if she were to die. "I did face the fact that it was a possiblity I might not make it," she said.

"It was very, very difficult. I wanted to see (my baby) grow up. I wanted to be there for him. But he also factored into my decision to have the transplant."

She was told she could stay on medication rather than have the transplant. But doctors couldn't guarantee the medicine would save her life. She could go into a "blast crisis," a critical stage where cancer cells start to reproduce rapidly, at any time. At the same time, there were also major risks with the operation, especially during the critical months after the transplant when she would be without an immune system.

"I didn't want to be wondering if it was going to get worse," she said. "I told myself if I'm going to make it, I'm going to make it now," she said, explaining why she chose the operation. It would reduce some of the uncertainties if she made it through the critical period, the first three months after the operation.

"I wanted to do it when (John Christopher) was young enough where it wouldn't affect him so much. I didn't get to see his first step. I didn't get to hear his first words," she said. "But I'm getting to see a lot of long term things I might not have been able to see otherwise."

Grohol said her attitude helped her get through worst parts. "After I went through the grief process, something everyone goes through, my whole attitude was, 'O.K., I'm young. I've got a whole life ahead of me.-Let's get on with life, ' " she said.

"There's a lot of bad things that you need to go through to get better," Grohol explained. And Grohol is better. She looks healthy and stays very active. "I just like to get outdoors and do things," she said. She and her husband water ski, wind surf, snow ski, play softball, ride motorcycles . . . "I'm busy," she said with a laugh.

"As far as I'm concerned, I'm cured. I don't live (cancer) everyday. I don't dwell on it. It's not something that haunts me," she said. "I look completely normal. I don't have any physical scars that people notice. A lot of good has come out of this. I've made a lot of friends and I think I've been able to help and encourage people (who have cancer)."

Grohol has counseled others with leukemia, mostly through referrals — some through Cancermount, a program through the American Cancer Society which attempts to match up people with similar type cancers, or close age group, so that the newly diagnosed patient can have somebody to talk to. She said it's sometimes hard on a cancer patient to have complete strangers approach them to comment on their condition. "I think it's invading sombody's privacy unless the person is open and public about it like Eileen is," she said. "But if a complete stranger comes up to you . . . and says 'Oh, I'm sorry, I heard you were sick,' it's uncomfortable."

Grohol said the best thing a person can do to help a cancer patient is to send cards and letters while they are in the hospital as well as donate a blood sample so their names will be on the national registry. However, she realizes that even if a match is made, it doesn't mean a life is saved.

She said scientists were doing research on patients who developed cataracts due to the radiation to find out how cataracts develop. She has slight cataracts and supports their research. "I feel like I am able to help out in that way," she said. She also tries to turn the trauma of the past into a positive future.

"I wondered for a long time why this happened to me. I feel like I can look back now and feel I'm special because a lot of people who have not experienced a life or death situation take things for granted," she said.

"I don't want to glorify a bone marrow transplant because it's not a sure thing," she said. "Not everyone is going to make it through it. Anything could go wrong because you don't have an immune system."

However, Grohol does see it as a way people can help others and said the odds of a cancer patient surviving are increasing.

"Technology and research are changing all the time," she said. Grohol said five years ago a bone marrow receipient left the hospital in about 60 days if everything went well. "Now people are an outpatient at anywhere from day 30 to 45. The progress is unbelievable," she said.

"I look at every day as a gift. That's what I feel it is."

BusinessWeek

OCTOBER 8, 1990 A McGRAW-HILL PUBLICATION

Personal Business

Health

A CHANCE TO SAVE THE LIFE OF A STRANGER

A year ago, Danny Storey, an Air Force equipment specialist in Milwaukee, agreed to donate bone marrow to a leukemia victim he had never met. The transplant was successful. Says an ecstatic Storey: "You're not giving up anything from yourself, but you have saved somebody's life."

Storey is one of 200,000 people who've joined the three-year-old National Marrow Donor Program (NMDP), which matches victims of fatal blood diseases with unrelated donors. The odds of finding a match is remote—just 20,000 to 1, which is why only 430 such transplants have been made so far. Still, those odds improve as more donors sign up. Corporations are joining the effort. In July, General Mills and Searle announced employee programs: The companies will pay the $75 cost of "typing."

Anyone from 18 to 55 and in good health can undergo this first step. An NMDP-affiliated blood bank or hospital will type your blood for basic human leukocyte antigens. The information is stored until you're given a preliminary match with a recipient, which could take years. There's a less than 20% chance you'll be called at all.

MANY TESTS. If you are, you undergo additional compatibility tests, a complete physical exam, and psychological counseling. "You know you're giving a specific person the only chance at life he has," says Tony Steele, coordinator of the NMDP at Belle Bonfils Memorial Blood Center in Denver. So far, over 50% of the recipients have survived.

If you feel you can't take it, this would be the time to back out. That's because the next irrevocable step is for the recipient to undergo rigorous chemotherapy aimed at destroying bone marrow so it can be replaced with yours.

Donating marrow is not simple. You are placed under general anesthesia while the marrow is extracted from your pelvic bones. Expect an overnight hospital stay and to ache for about 10 days.

The marrow, meanwhile, is rushed to the recipient for transplant within 24 hours. You'll know only the patient's first name and age, but you'll be kept informed about his or her status. Once the procedure is completed, however, the two of you can exchange names and even meet. The family of one leukemia victim who died actually listed his donor among his survivors.

Because of the emotional impact, the NMDP (800 654-1247) initially limited people to one donation, but it's reconsidering. That's because of donors such as Maria Gaitan-Endres, a property manager in McLean, Va. She gave marrow to a 33-year-old West Coast leukemia victim in August. The outcome is still in doubt, but she found the experience so rewarding that "I'd give again in a heartbeat."

Sandra Atchison

BONE MARROW RECIPIENT JAY GIBSON AND DONOR DANNY STOREY

PHOTOGRAPH BY MICHAEL L. ABRAMSON